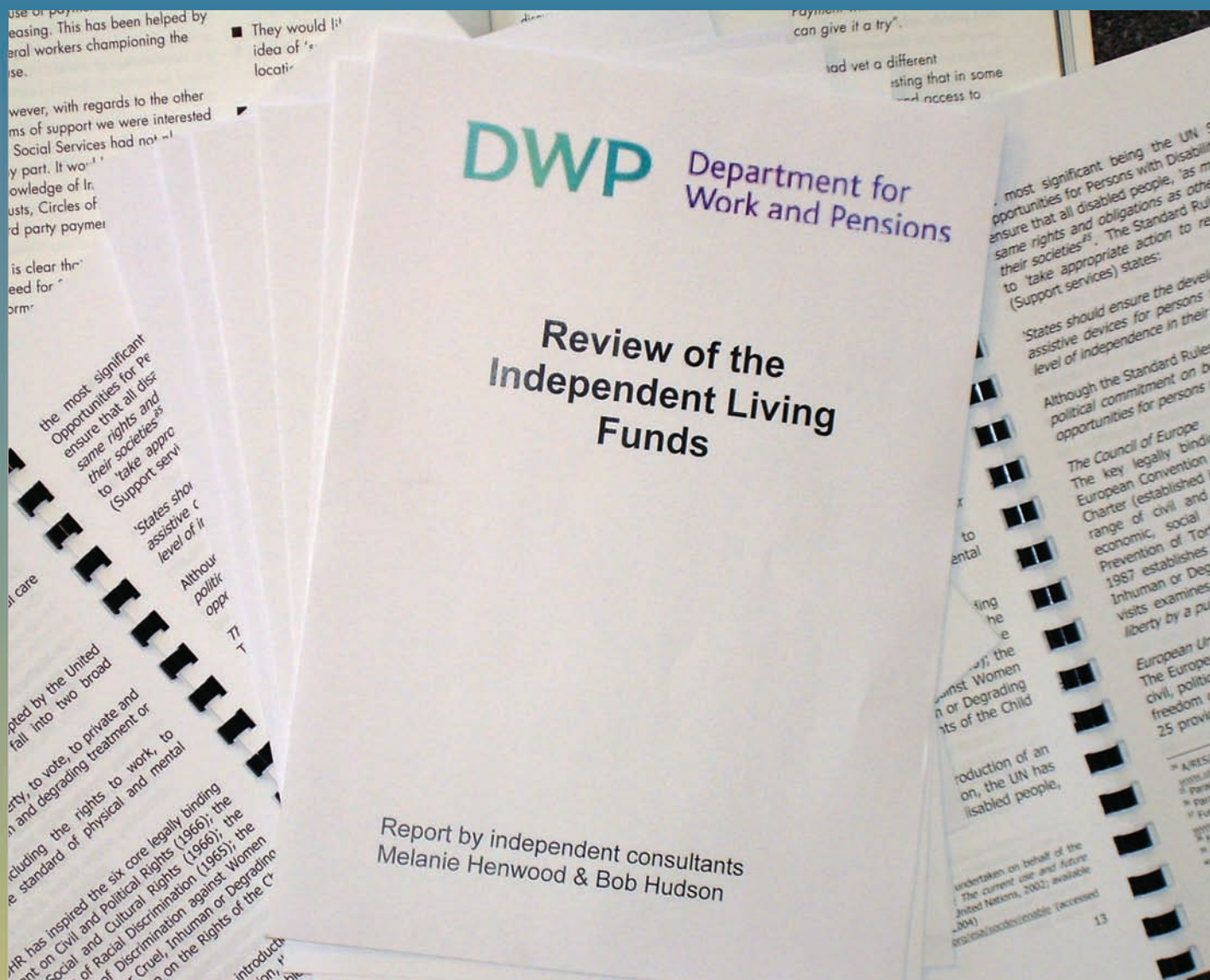


INDEPENDENTLY

NEWSLETTER

April 2007



Independent Living Funds review is out! (see page 04)

The newsletter from NCIL for disabled people
about Independent Living, Direct Payments,
Personal Assistance & more...

Also available in large print, Braille, audio tape, PC floppy
disc, email and on Website



National Centre for
Independent Living

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Readers are advised to check details for themselves and make their own judgements about the merits of the products, services or events offered.

Charity no.1113427

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Information Disclaimer:

Independently provides an opportunity for the exchange of information.
All the views expressed are not necessarily the views of NCIL.
We reserve the right to edit articles.

The long awaited Independent Living review has been released and NCIL is welcoming the recommendations that have come out of the review.

Sue Bott – Strategic Director for NCIL says;

“The National Centre for Independent Living is broadly in support of the recommendation in the report ‘Reviewing the Future of the Independent Living Funds’ which has been produced for the Department of Work and Pensions by independent consultants Melanie Henwood and Bob Hudson, published today.

In particular, NCIL is in support of the recommendation not to transfer the ILF to local authorities. As the report rightly observes: -

“We need to avoid a rerun of the FACS (Fair Access to Care) scenario in which LAs have the discretion to ration eligibility for support in ever-decreasing circles.”

Menghi Mulchandani, Chair of NCIL comments ‘The ILF has made a difference to thousands of disabled people enabling us to live independently and have control over our lives. This would never have been achieved had matters been left to local authorities alone. We are opposed to the transfer of the ILF to local authorities now or at any time in the future.’

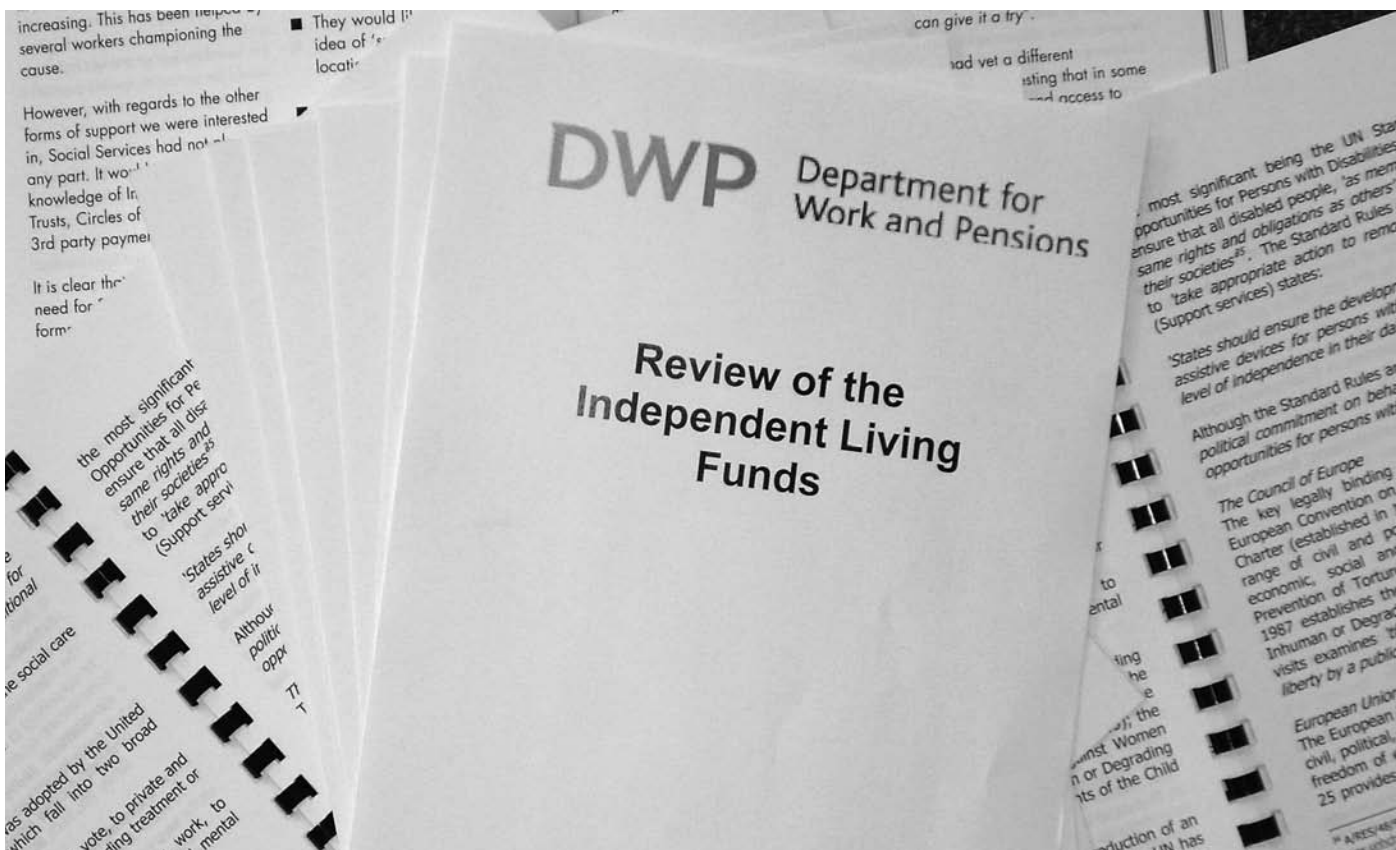
NCIL is now urging the Government to ensure that the long-term future of the ILF and the drive towards personalised budgets, which NCIL fully supports, involves disabled people and our organisations. This is in line with the report from the Prime Minister’s strategy unit ‘Improving the Life Chances of Disabled People’ for a user-led organisation in every locality based on the model of existing centres for independent living.

Whilst NCIL welcomes the recommendations as a whole to widen the remit of the ILF, to increase those eligible to apply for support, to increase publicity about the ILF and to improve structures and governance, NCIL is concerned that without additional resources the ILF will not be able to meet the demand on its resources.

It is no use arranging the deckchairs on an ILF ship that is sinking due to lack of funds. Support and extension will require a cash injection. This is badly needed if independent living is to be a reality in disabled people's lives. Ministers are urged to take urgent action to address the crisis in resources for social care and to halt the process of disabled people's lives being reduced to a mere existence which is unacceptable in a modern society.

We await the Government response to the review which we expect in the summer but in the meantime NCIL is in the process of producing a policy briefing that will be sent out to all Centres for Independent Living and can be made available to any individual who requests it. If you would like a copy of the report and 68 recommendations it is now available on the Department for Work and Pensions website www.dwp.org.uk including an Easy Read version.

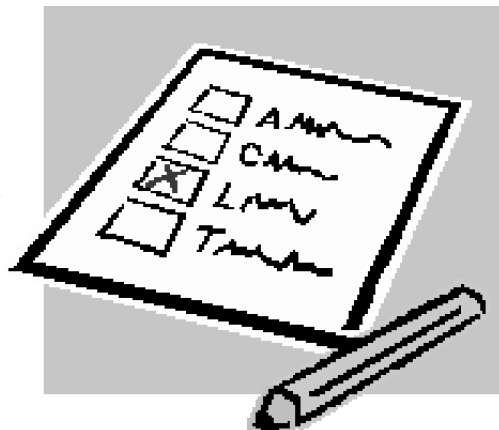
Copies of the report can also be ordered from Jane Cocking, Department for Work and Pensions, The Adelphi, 1 – 11 John Adam Street, London WC2N 6HT or by contacting the ILF on 0845 601 8815



NCIL reported in the last edition about the Independent Living Campaign. This report is an update on what is happening with the campaign and how you can get involved

How is the campaign going?

NCIL organised a series of regional meetings about the campaign. At the meetings, the campaign got strong support from disabled people and our organisations in those areas. There is clearly a lot of anger and frustration among disabled people who see our organisations in difficulty and disabled people finding it is harder and harder to get support for any thing that goes much beyond basic personal care. Independent living has always been about including disabled people in the whole of our society and we want something which will make this more of a reality for disabled people today.



At national level, we have good support from our own organisations, with Essex, West of England, Southampton, Derby and a number of London based CILs all involved. There is also good support from a number of other national groups such as Disability Rights Commission (DRC), Alliance for Inclusive Education, People First, United Kingdom Disabled Peoples Council (UKDPC), Equalities, Scope, Radar, Mind, Action for Advocacy, the Equal Opportunities Commission and the Commission for Race Equality, all organisations are contributing time and resources to the campaign.

The campaign is lively, growing, timely and fundamentally important to us all. Now is the time to get involved!!!

How can we get involved?

Membership of the campaign is free to individuals and organisations. The more people who join the campaigning the better chance we have of getting the new law.

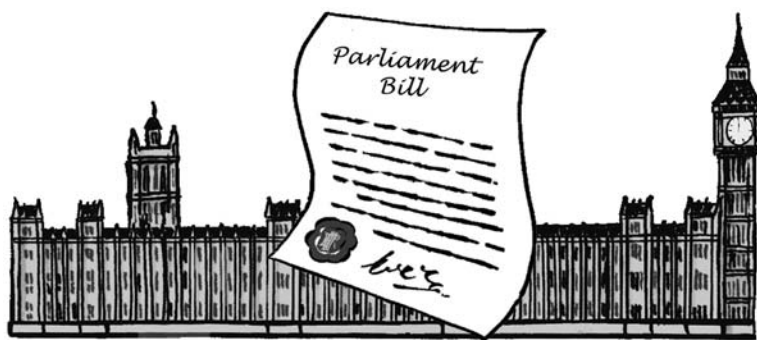
We are developing a campaign pack, filled with practical suggestions and

campaign materials for you to use. You can these directly from NCIL. You will get information from us on a regular basis about the campaign. We want to hold a national launch of the campaign in London on the 20th of June 2007. We are planning to support people with some subsidised transport to the event (venue not yet confirmed please see contact details below to obtain more details). There will be a number of top name speakers and an opportunity to bring together disabled people from all over the country and draw attention to the campaign and the Bill.

You can organise campaign activities locally, such as possible lobbies of local authorities to ask them to pass motions at their annual meetings to support the Bill. At the same time, to open discussions locally about implementing parts of the Bill now using the Disability Equality Duty and the need to actively involve disabled people in drawing up Disability Equality Plans.

Why is the Bill important?

The Bill has arrived at exactly the right moment for us. The Bill is based securely on the demands of the independent living movement, easily recognised by many who have been involved over the last 20-25 years. It has our DNA!



The Bill deals with both the growing crisis in social care and the growing problems faced by disabled peoples organisations. It also provides the Government with a way of solving what is now becoming a widely recognised failure of the social care system.

The Government needs the Bill to achieve its targets of full equality for disabled people by 2025, its new strategy on health and social care and will enable local authorities to meet their new duties under the Disability Discrimination Act (DDA) 2005.

Much more importantly, the Bill will give every disabled person the right to a minimum level of support, guaranteed to enable them to meet minimum targets for active involvement in their family, community and wider society.

Other key points in the Bill are:

- The right to choose where you live.
- The right to self advocacy
- The right to advocacy support



- ▶
 - The right to a portable support program
 - The right to accessible housing
 - A new duty on local authorities to support and promote local groups within their community, including disabled peoples organisations

What do we need to do now?

The Bill has good support in the Lords and some support among MPs. The other political parties, both Conservative and Liberal Democrat, support the Bill, with some reservations on costs.

We now need to build a strong and vibrant campaign which will convince the Government that they can't ignore this Bill. When it comes to the Commons it will only make progress if it has Government support.

We can push our MP to sign the Early Day Motion number 334, supporting the Bill. We are organising another national demonstration and lobby of Parliament in October 2007, to coincide with the ballot for private members Bills which will be happening about that time. More details later.

You can use our postcard campaign to support the Bill. Most importantly we need the active support of as many disabled people and disabled peoples organisations as possible in building campaign at the Grass Roots level.

We need to be working together with as many different organisations from within our community as we can. The campaign appeals to a wide group of people and we need to build an inclusive and radical campaign that can bring these different sections of our communities together.

How can I get more information?

Contact policy@ncil.org.uk or contact NCIL by one of the contacts below. We will include you in our mailing list on the campaign. You can also get information from our website and get involved in debate through our forums, these are also available on our website www.ncil.org.uk or from;

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Head of Policy

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EXPERTS BY EXPERIENCE

Firstly, can I say a big thank you to all the people who responded to our article on becoming an Expert by Experience. The National Centre for Independent Living took numerous enquiries about this exciting new role. Most of the regions across the country have now interviewed and recruited Experts, and the training will shortly be underway. User led organisations in each of the nine regions are working with NCIL to deliver the project and these organisations will be supporting Experts in their role.

Through our partnerships NCIL will be inspecting approximately 234 domiciliary care agencies. Experts will be trained and deployed across the country to talk with people who use domiciliary care from various agencies. Each Expert will be focussing on different outcomes including:

- Quality of life
- Exercising choice & control
- Making a positive contribution
- Personal dignity and respect
- Freedom from discrimination and harassment
- Improved health and wellbeing
- Having control over your money and resources
- Leadership and management



Jenny Orpwood, one of the Experts by Experience

Experts will be gathering information in a variety of ways and in a variety of settings, they will be writing a report which will be given to the Commission's Inspector. The Inspector will then merge the reports together and the report will be sent to the Domiciliary Care Agency and will eventually be published on the Commission for Social Care's website, on www.csci.org.uk

If you use a care agency to meet your needs you are able to check what the Commission has to say about the agency on their website.

This is an exciting project giving people who use services the opportunity to provide their expertise, knowledge and skills, about what its like to receive a service, consulting with other people who use services, reporting and eventually shaping the way services are delivered. The experience and expertise of people who use services is now being recognised and the Commission for Social Care is hopefully creating the foundations for real user involvement and recognising the cost of user involvement.

Sandy Marshall
Project Manager

THE FUTURE OF USER LED ORGANISATIONS

Over the past two months NCIL has held consultation meetings in Doncaster, London and Coventry to discuss the future of user-led organisations and the campaign for the independent living bill.

These are interesting times for our organisations: on the one hand seeing our funding cut and some of us going out of business; on the other hand a commitment in *Enhancing the Life Chances of disabled People* for a user-led organisation modelled on existing Centres for Independent Living (CILs) in every locality. So there was much to discuss.

Most agreed that CILs should be 100% controlled by disabled people although it was accepted that for some organisations the involvement of others might be a necessary part of their development.

There was much talk about what CILs actually do. Several people mentioned the need to revisit the twelve needs of independent living: information, counselling and peer support, housing, technical aids and equipment, personal assistance, transport, access to the built environment, inclusive education and training, adequate income, equal opportunities for employment, advocacy, and adequate and appropriate health care.

It was recognised that because of various reasons, like a lack of resources, CILs needed to reach out to be inclusive of all impairment groups. What was really good about the events was the sharing of information between all those present which resulted in some groups offering to help out other groups.

There were also ideas about what NCIL should be doing nationally to support CILs. These ideas included providing summaries of key documents and legislation, provide information regarding funding and sustainability, develop and support regional networks, and support CILs with quality standards and accreditation.

Caroline Ellis from the Disability Rights Commission spoke at all three events. She outlined what was in the Independent Living (Disabled Persons) bill and suggested ways for people to become involved. See

elsewhere in this publication for where we are at with the campaign. For the campaign to build it is important to start raising the bill locally and get pledges of support. Some groups have already started discussing the bill with their local authorities.

Talking of campaigning led on to a discussion about charging for community care services. This has stimulated NCIL into restarting the Coalition Against Charging. Shortly we will be producing a brief on how the Disability Equality Duty can be used locally to challenge charges.

It is easy to become bogged down in the negative things that have happened to our organisations in recent times but there are some good opportunities now for us to take advantage of.



FREQUENTLY ASKED QUESTIONS

Can I pay a relative living in the same house with my direct payment?

The Department of Health Guidance states that



“Unless a council is satisfied that it is necessary to meet satisfactorily a person’s needs, a council may not allow people to use direct payments to secure services from a spouse (husband or wife), from a partner (the other member of an unmarried couple with whom they live), or from a close relative (or their spouse or partner) who live in the same household as the direct payment recipient.

This restriction is not intended to prevent people using their direct payments to employ a live-in personal assistant, provided that that person is not someone who would be usually excluded by the Regulations. The restriction applies

where the relationship between the two people is primarily personal rather than contractual, for example, if the people concerned would be living together in any event”

In short, the Local Authority needs to be convinced that this is the best way to satisfactorily meet the needs of the direct payment user. This could be situations where there are cultural issues to be taken account of, or where it is felt because of certain specific needs that the only person able to meet the need is the close family member. It is clear that this should not be a standard way of meeting the assessed needs, but an exception.

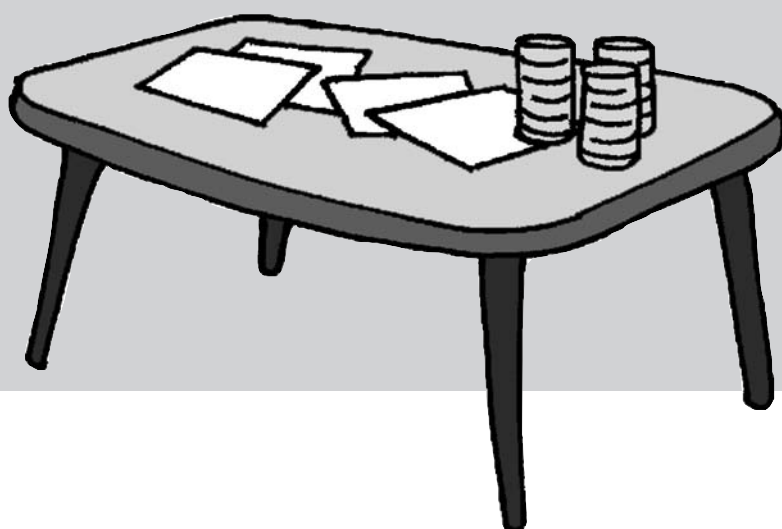
The issue that the direct payments users need to consider in these circumstances is if difficulties arise i.e. the person is not doing the job in a way in which you want it, will they be able to resolve those difficulties when it is a

close family member and you share the same home. If disciplinary procedures are necessary would the direct payment users feel comfortable undertaking this and how would it affect the future relationship in the home.

Whilst it may seem like the best solution at the time, and the above circumstances are not common, it is an issue for people who have gone down this route and as a result could find themselves trapped into a working relationship that they cannot easily extract themselves from without causing all sort of personal relationship difficulties.

Having said that, it can also work well when needed and provided a clear working relationship is agreed at the start that includes a job description, contract and agreed procedures, the chance of a positive relationship is greater.

If you would like more information on this please contact our Information Manager,
Wendy Gross on 02075871663
Or email info@ncil.org.uk



The Roles and Functions of Social Workers

Many disabled people will, undoubtedly, come into contact with a Social Worker at one stage or another in their life, whether it is to have an assessment for social care or for other reasons. The General Social Care Council (GSCC) is currently examining the roles and functions of this role and NCIL, Shaping Our Lives and one or two other disabled people who use services have been attending the reference group.



A three month consultation was launched on March 14th, this will give people who have had experience working as, or with social workers, the opportunity to share their view of what social work looks like at its best in today's society.

The project has been commissioned by the Department of Health and the Department for Education and Skills and follows on from the *Options for Excellence: Building a Social Care Workforce for the Future* review. Working alongside the GSCC are the Commission for Social Care Inspection (CSCI), the Social Care Institute for Excellence (SCIE), the Children's Workforce Development Council (CWDC) and Skills for Care (SfC).

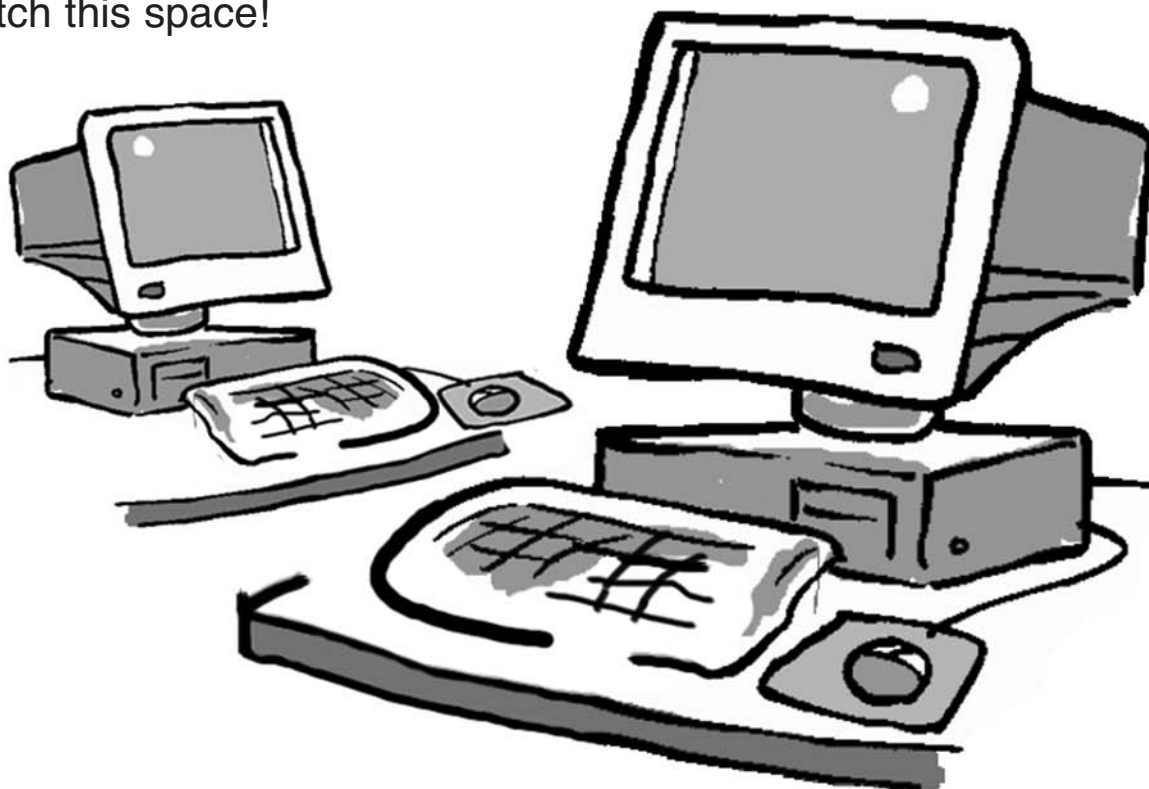
An online consultation document was been published on the 14th March setting out views on the roles, tasks and value of social work. Service users and others from social care and related sectors are invited to comment on the issues set out in the document building from their individual perspective and experience. The responses to the consultation will inform a final statement defining the roles and tasks of social workers which will then be presented to Government in the summer.

The consultation paper is available on the GSCC website alongside supporting information that should be considered before sending in your views. The response questionnaire, available online or in hard copy, will be available at www.tribalgroup.co.uk/GSCC-consultation shortly.

Due to unforeseen circumstances, the date for our new look website has been delayed, our apologies to anyone who has been looking out for the 'New Look'. We are working very hard here at NCIL to provide you with this much needed resource and ask you for your patience. The old website is in need of some updating so please do not hesitate in contacting us if you need information that is not available.

We have now finished an extensive mapping exercise that has given us up to the minute information about direct payment support services, centres for independent living and social service departments, which will all be at your fingertips once the new site goes live.

Watch this space!



A 'FIRST' IN KENT

The Centre for Independent Living Kent (CILK) is delighted to announce the launch of the **FIRST** Mobile Centre for Independent Living in the UK.

This exciting project, funded with a grant of £174,202 from the Big Lottery has funded a new wheelchair accessible vehicle (mobile office), the salary of a manager and provide volunteering opportunities which will not only help CILK give much better support to existing members but will enable disabled people across the county to access independent living support right on their own doorstep. The manager and disabled volunteers staffing the mobile will give advice and guidance on all aspects of independent living.

The vehicle is now ready to take to the roads and will cover all areas in Kent including Ashford, Dartford, Maidstone, Thanet, Tonbridge and the Medway Towns and will provide advocacy, peer support, information covering all aspects of independent living including assisting those who are already receiving direct payments and those wishing to become direct payment users, information on aids and equipment and much, much more.



If you would like more information regarding this new initiative please call Centre for Independent Living Kent on 01622 355777 or go to their website www.cilk.org.uk

BUSINESS SUPPORT FOR **DISABLED ENTREPRENEURS**



Disabled Entrepreneurs can gain support for starting a business this spring and summer, thanks to De Montfort University (DMU) in Leicester. DMU's Business Incubation and Enterprise Department will be running a scheme to help disabled people in the East Midlands into self-employment. The programme will begin with a short course, 'Starting in Business', followed by individual mentoring and is funded by the European Social Fund and supported by the East Midlands Development Agency (EMDA).

Stuart Hartley, Project Manager for Business Incubation and Enterprise at DMU, said: "This programme aims to provide the basic skills and knowledge needed to set up and run a business, helping people to get their ideas off the ground and giving them the best chance of success."

The course will cover how to write a business plan and issues such as finance, sales, marketing and business growth. An introductory session will take place on Saturday 21 April at DMU's Graduate Business School on Western Boulevard. This will be followed by one-day courses on Saturdays 19 May and 2, 16 and 30 June.

The course costs £50 and help with payment may be available depending on individual circumstances.

To find out more call 0116 207 8914, email ceo@dmu.ac.uk see www.dmu.ac.uk/ceo or text 'ceo' plus your query to 07797 805 451.



DIRECT PAYMENTS: BANKING ISSUES



In the last edition of INDEPENDENTLY we reported briefly on a response that NCIL had received in relation to concerns that they had raised with the Department of Health. This article gives more details on the issues raised by the Department of Health (DOH) to the British Banker Association by the Secretary of State, Patricia Hewitt.

In summary the issues raised were

- Proof of identity as a result of disabled people often not having passports or driving licences despite having a letter of introduction from their social services to present to the bank explaining about direct payments.
- Individuals not being able to physically sign cheques
- Unauthorised transfer of monies from Direct Payment accounts into personal accounts when the personal account has gone overdrawn leaving Direct payment users short of money to pay their staff and meet their needs.
- Difficulties obtaining the necessary bank account to have access to a cheque book due to poor credit history making it difficult to pay staff and provide the necessary audit trail for local authorities.

The responses received back from the British Bankers Association are summarised below;

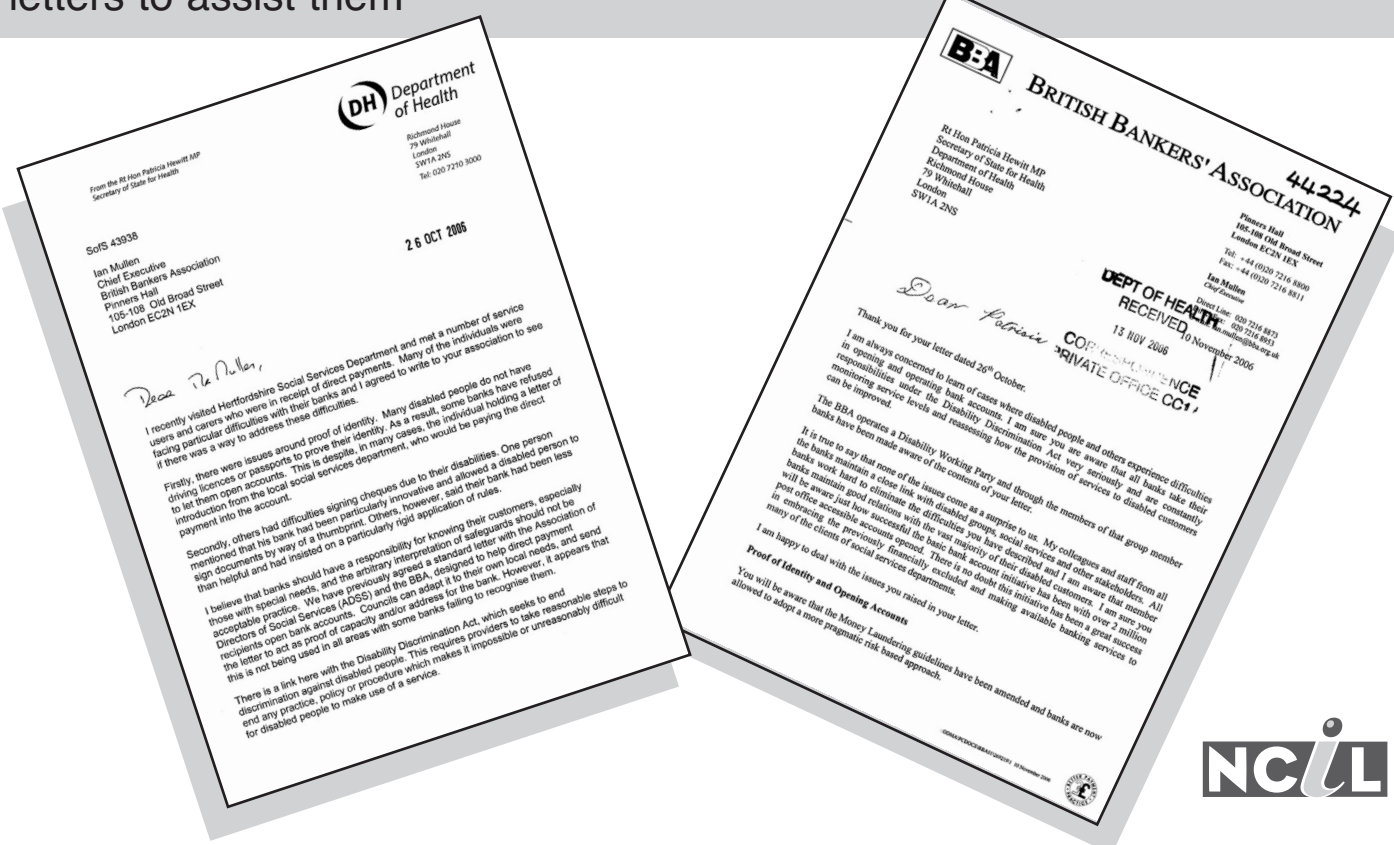
- **Proof of identity** - In all cases concerning clients of social services departments it should be possible to arrive at a suitable form of identification, letters concerning pension or benefit entitlement and confirmation of identity from a social services manager are normally acceptable.
- **Inability to sign cheques** - This should not happen as all banks have arrangements in place to facilitate the use of cheques by cus-

tomers who are disabled, Customers who use a rubber stamp to apply a signature for other purposes may agree this method with their bank. Obviously security is paramount and it may be that some customers will feel safer using other methods of making payments by way of electronic banking or standing orders for example.

- **Transfer of funds without authorisation** – BBA members are aware that funds should not be taken from separate designated basic bank accounts used solely to collect direct payments to settle debts on another account.
- **Use of a cheque book** – The guidance provided by the Department of Health makes it clear that cheque books are not issued on basic bank accounts. Customers can set up direct debits and most banks will allow standing orders, some banks will also permit internet and telephone banking on basic bank accounts.

(please refer to the actual letters for the full responses)

A full copy of both letters can be found on the department of Health Website www.dh.gov.uk and search for British Bankers Association and direct payments or call NCIL who will be able to help. Direct payment users who are finding difficulties with their banks may want to use these letters to assist them



THE STATE OF SOCIAL CARE IN ENGLAND 2005 - 06

INDEPENDENTLY reported in the last issue that Commission for Social Care Inspection (CSCI) had issued their latest report entitled '*The state of social care in England 2005 – 06*'. The report is a lengthy one, although there is an executive summary in easy read, large print and audio version. We recommend that you try and obtain a copy but have included below a section that details the impact that the current state of social care is having on individuals.



The report covers a number of different subjects providing information on key areas. The report shows that there has been an increase in the use of direct payments with payments to children and carers of disabled children seeing a three-fold increase. It is interesting to note though that direct payments still accounted for only around £1 in every £100 of social care expenditure by councils in 2004-05, and despite the expected growth in 2005-06 still remains at very low levels.

What is interesting to note is the section on the impact of the current state of social care on the people that are expected to benefit from its provision (see below). You will see that despite the fact it is reported that there has been an overall increase in spending throughout 2005 -06 the impact of social care is still not a positive one!

(please note the text opposite is taken directly from the report)

"The impact on people of the current state of social care"

From this overview of the state of social care, the following groups of people, including children and families, currently using social care services or seeking support give rise for concern:



1. **Those people who are not using services arranged by the council but who seek support and good information about what may be available.** As yet, there is limited evidence as to whether people are successfully directed to alternative and appropriate support or properly informed about the options open to them.
2. **Carers**, unpaid relatives and friends who are bearing the costs of ever-tighter eligibility criteria for services.
3. **People who have little, if any, choice and control over the services they use.** There are still too many people who are offered little, if any, choice of services; nor do they have any choice as to who comes into the privacy of their homes to provide assistance and when and how support is provided. Too many children are moved around frequently, denying them the stability that would improve their life chances.
4. **People who are using services that are not meeting all the national minimum standards and are simply not good enough.** Even if not at risk of harm, some children and adults, including those who care for family members, are being denied a good standard of care and decent quality of life as well as the social, educational, and work opportunities others would expect. The educational attainment of children in care is still short of the level achieved by all children. ►

► 5. **People with complex needs whose specialist needs in addition to their ordinary needs are not being met.**

Children and adults with complex needs or challenging behaviour are not always offered the special set of services that mean they can live their lives with dignity.”

The summary concludes by saying;

“Despite progress and some real success stories, there is a pressing agenda of change to close the gap between government policy aims and the reality of many people’s experiences.”

If you would like to see the summary or obtain your own copy you can download it from www.csci.org.uk or call 08450150120, textphone 08450152255, or email enquiries@csci.gsi.gov.uk

SUPPORT NCIL

You can get involved and support NCIL by:

Making a donation

Sponsoring one of our activities

Taking part in one of our campaigns

Contributing to our newsletter

Joining as a member

Using our training services

Contact us

General information: info@ncil.org.uk

Campaigning: policy@ncil.org.uk

Training and consultancy: contracts@ncil.org.uk

Finance & administration: office@ncil.org.uk

NCIL is a company limited
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Charity no.1113427

We specialise in domestic payroll
You specialise in how to run your life
Together we can make independent living a reality



For more information on our services, call Enable Payroll
on 0845 226 2213 or email info@enable-payroll.co.uk

www.enable-payroll.co.uk

Fixed-fee all-inclusive specialist payroll service
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WHEN YOU TAKE ON A DIRECT PAYMENT SCHEME you will most likely employ people yourself, rather than use an agency to do it for you. But becoming an employer for the first time can be a source of great concern. Without working knowledge of the tax system and current employment law, you are entering a potential minefield.

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WE SPECIALISE IN DIRECT PAYMENTS and we understand the challenges you face when you employ a personal assistant using Direct Payments. We give unlimited advice and guidance on all pay and employment related issues, there is no meter running when you use Enable Payroll

OUR WEBSITE meets the WAI's AA compliance standards and our literature is suitable for most user groups.

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